

**THE ELIGIBILITY DEFINITION USED IN THE SOCIAL SECURITY ADMINISTRATION'S
DISABILITY PROGRAMS NEEDS TO BE CHANGED**

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Introduction

In its October 2003 report on the definition of disability used by the Social Security Administration's (SSA's) disability programs [i.e., Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) for people with disabilities], the Social Security Advisory Board raises the issue of whether this definition is at odds with the concept of disability embodied in the Americans with Disabilities Act (ADA) and, more importantly, with the aspirations of people with disabilities to be full participants in mainstream social activities and lead fulfilling, productive lives. The Board declares that "the Nation must face up to the contradictions created by the existing definition of disability."

I wholeheartedly agree. Further, I have concluded that we have to make fundamental, conceptual changes to both how we define eligibility for economic security benefits, and how we provide those benefits, if we are ever to fulfill the promise of the ADA.

To convince you of that proposition, I will begin by relating a number of facts that paint a very bleak picture – a picture of deterioration in the economic security of the population that the disability programs are intended to serve; a picture of programs that purport to provide economic security, but are themselves financially insecure and subject to cycles of expansion and cuts that undermine their purpose; a picture of programs that are facing their biggest expenditure crisis ever; and a picture of an eligibility determination process that is inefficient and inequitable -- one that rations benefits by imposing high application costs on applicants in an arbitrary fashion.

I will then argue that the fundamental reason for this bleak picture is the conceptual definition of eligibility that these programs use – one rooted in a disability paradigm that social scientists, people with disabilities, and, to a substantial extent, the public have rejected as being flawed, most emphatically through the passage of the ADA. Current law requires eligibility rules to be based on the premise that disability is medically determinable. That's wrong because, as the ADA recognizes, a person's environment matters. I will further argue that programs relying on this eligibility definition must inevitably: reward people if they do not try to help themselves, but not if they do; push the people they serve out of society's mainstream, fostering a culture of isolation and dependency; relegate many to a lifetime of poverty; and undermine their promise of economic security because of the periodic "reforms" that are necessary to maintain taxpayer support.

I conclude by pointing out that to change the conceptual definition for program eligibility, we also must change our whole approach to providing for the economic security of people with disabilities. We need to replace our current "caretaker" approach with one that emphasizes helping people with disabilities help themselves. I will briefly describe features that such a program might require, and point out the most significant challenges we would face in making the transition.

Many of the statistics I will cite are based on analyses of Current Population Survey (CPS) data that appear in Stapleton and Burkhauser, eds. (2003) or at the website of Cornell's StatsRRTC, www.disabilitystatistics.org. The CPS disability measure, based on self reported "work limitations" has been quite rightly criticized for its lack of a sound conceptual basis and difficulty of interpretation (Hale, 2001; NCD, 2002). Extensive analysis has shown, however, that employment rate trends for people with disabilities as measured in the CPS are quite similar to those measured in the National Health Interview Survey and the Survey of Income and Program Participation, using preferred measures of disability (Burkhauser, Daly, Houtenville and Nargis, 2002; Burkhauser, Houtenville and Wittenburg, 2003). Further, as will be seen, the statistics from the CPS tell a story that is very consistent with statistics obtained from SSA administrative data.

A bleak picture

The Decline in Economic Security of People with Disabilities

The first set of statistics I will present provides convincing evidence that working-age people with disabilities are losing ground relative to others with respect to household income, achievement of economic independence, and integration into the workplace.

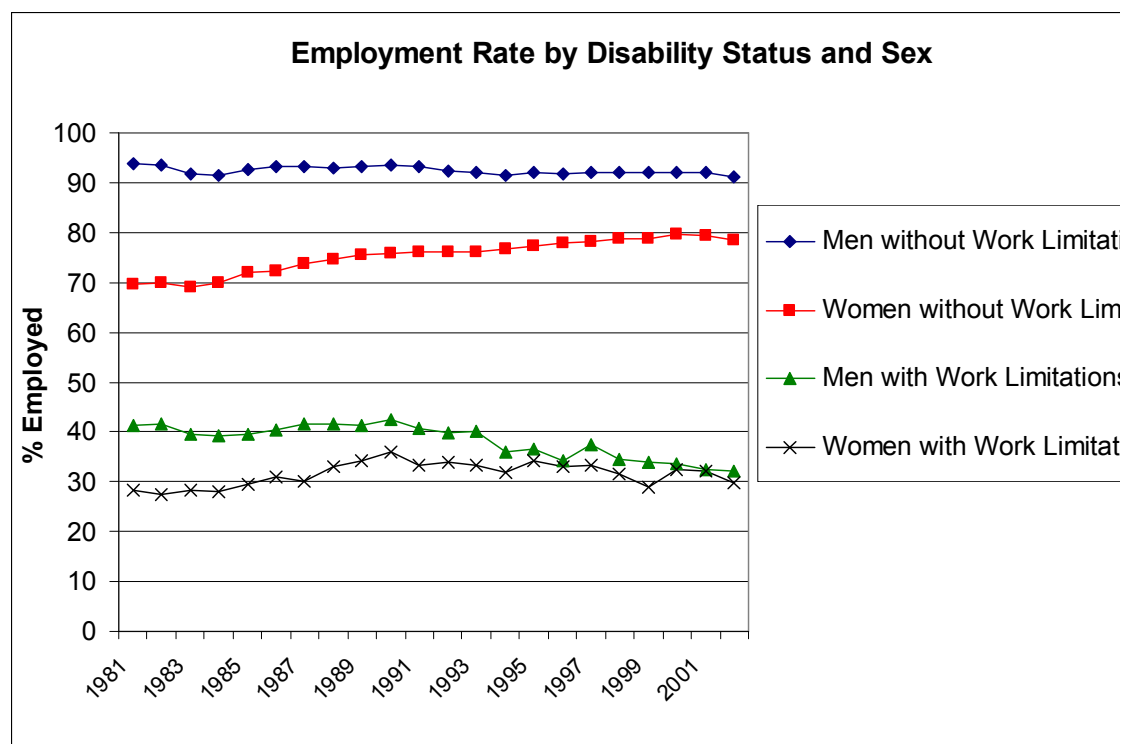
Household incomes of working-age people with disabilities fell further behind those of other households in the 1990s. The conventional wisdom is that the exceptional economic expansion of the late 1990s lifted all boats, but in fact one group's boat didn't rise with the tide. Inflation-adjusted median household incomes for working-age men with disabilities *fell* from the business cycle peak of 1989 to the business cycle peak of 2000 by an estimated 5.1% – a period over which median household incomes for those without disabilities increased by 6.8% (Burkhauser, Daly and Houtenville, 2001; Burkhauser and Stapleton, 2003a). Households of working-age women with disabilities fared somewhat better, with an increase in median income of 4.5% over the same period, but that increase was well below the 10.2% increase for households of women without disabilities.

During the same period, working-age people with disabilities became substantially less reliant on their own earnings, and more reliant on SSA disability benefits (i.e., SSDI and SSI). For men with disabilities, the share of household income accounted for by own earnings dropped from 38.0% in 1989 to 27.6% in 2000, while the share of household income accounted for by disability benefits increased from 14.2% to 20.6%. For women with disabilities, own earnings increased somewhat as a share of household income, from 21.7% to 23.5%, but the share of income from benefits increased substantially, from 10.2 to 15.9%.

The proximate cause of these trends was a decline in the employment of people with disabilities, which began with a sharp decline during the 1990 recession, continued without interruption through the subsequent expansion, albeit at a slower rate, then accelerated again during the more recent recession. There is currently no sign of a recovery. After almost a decade of relative stability, the employment rate for men with disabilities fell by 20.4% from 1989 to 2000 -- from 41.2% to 33.6% (**Exhibit 1**). Over the same period, the employment rate for men without disabilities also declined, but only slightly -- from 93.2% to 92.1%. The decline in the employment rate for women with disabilities was much less than for men, from 34.3% to 32.5%, but that compares to a sharp increase in the rate for women without disabilities, from 75.5% to 79.6%.

These trends are mirrored in changes in the disability prevalence rates for the SSDI program. From 1990 to 2002 the number of SSDI beneficiaries per 1,000 insured increased by 44.0%, from 25.0 to 38.8. Although the increase is partly due to the aging of the baby boom generation, increases occurred in every age category (**Exhibit 2**). Except for the oldest age group, prevalence in 2002 was even substantially higher than it was in 1980, before the tightening of eligibility criteria that occurred in 1981.

Exhibit 1. Trends in the Employment Rates of People With and Without Work Limitations, by Sex

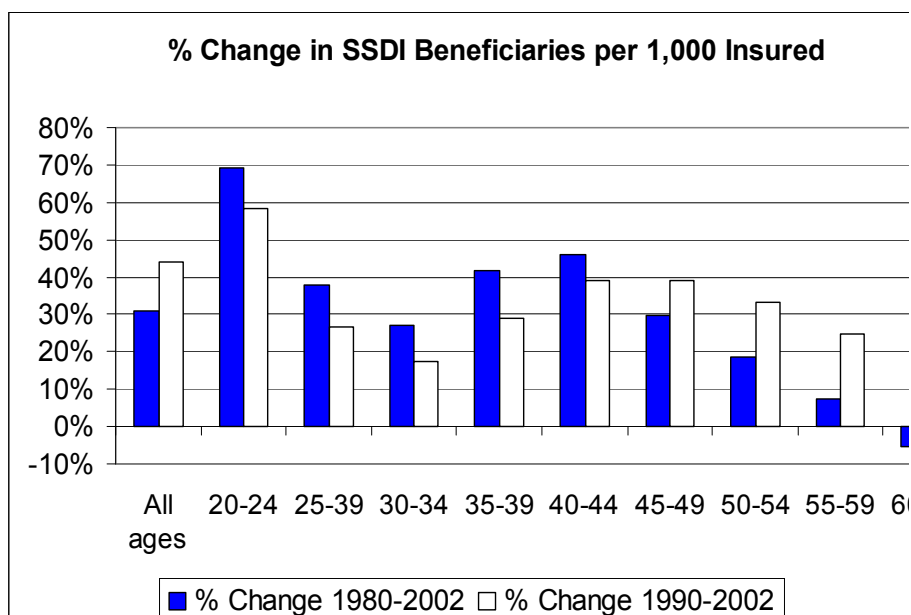


Source: Current Population Survey estimates, from Cornell University's StatsRRTC, www.disabilitystatistics.org.

Working-age people with disabilities also became much more dependent on public health insurance. From 1990 to 2000, the percentage of working-age people enrolled in Medicare because of disability increased from 2.1% to 3.0%, a 37.8% increase, while the percentage enrolled in Medicaid because of disability increased from 2.3% to 4.1%, a 57.8% increase.¹

¹ Medicare and Medicaid enrollment are from Tables 3.6 and 3.31 of CMS (2004). Population estimates for person aged 18 to 64 are from SSA (2003a).

Exhibit 2. Percent Change in SSDI Prevalence, by Age, 1980 - 2002 and 1990 - 2002

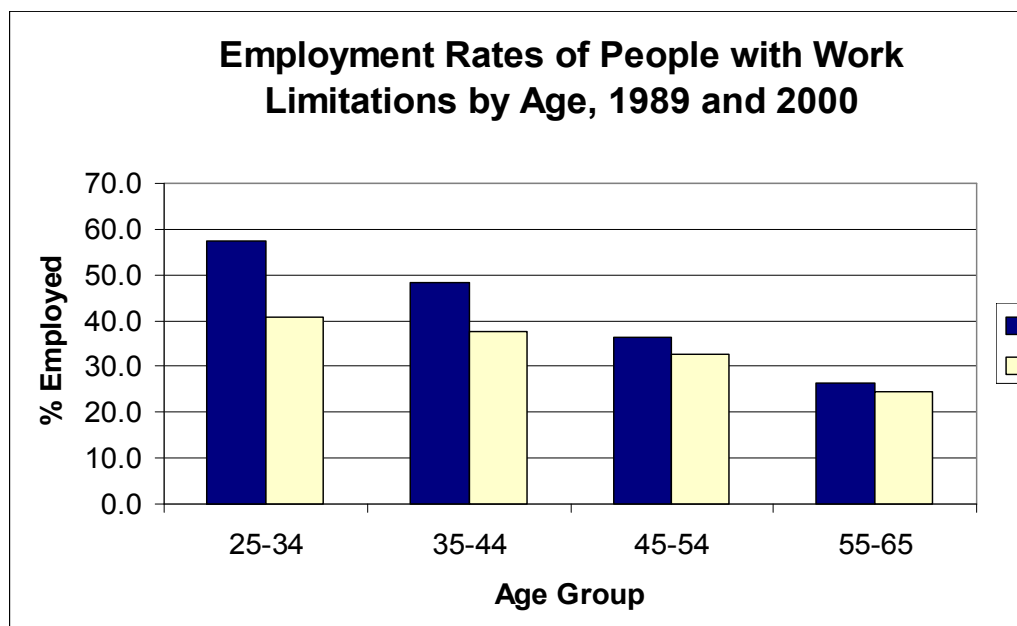


Source: Social Security Advisory Board (2003).

A troublesome feature of this pattern of household income decline, declines in self support, and increased dependence on public programs is that the trends are stronger in younger age groups than in older age groups. This is apparent in the SSDI prevalence data. Similarly, employment data show that the employment rate declined by 34.2% for people with work limitations aged 25 to 34, compared to just 7.4% for those aged 55 to 64 (**Exhibit 3**).

In summary, household incomes for the population that SSA's disability programs serve are falling, and this population is increasing its dependence on public income and health benefits. More and more young people with disabilities, especially, are becoming dependent on public support. A large share of them are likely to live their lives in poverty as a result.

Exhibit 3. Employment Rates for People with Work Limitations by Age, 1989 and 2000



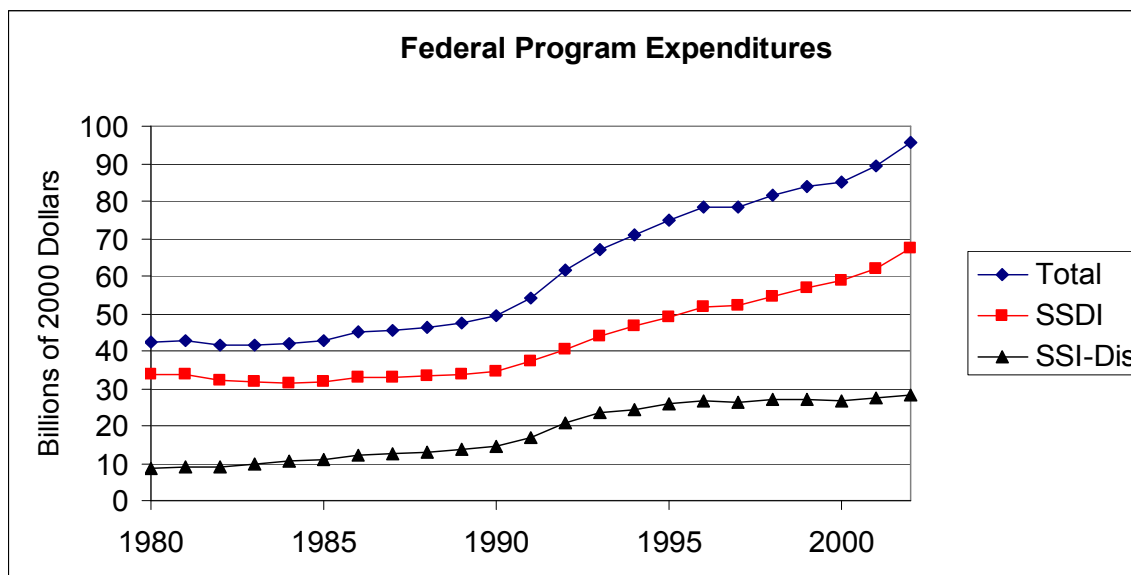
Source: Houtenville and Daly, 2003

Disability Program Expenditure Growth and Taxpayer Support

The next set of facts concern SSA disability program expenditures and the capacity of the government to finance the disability programs.

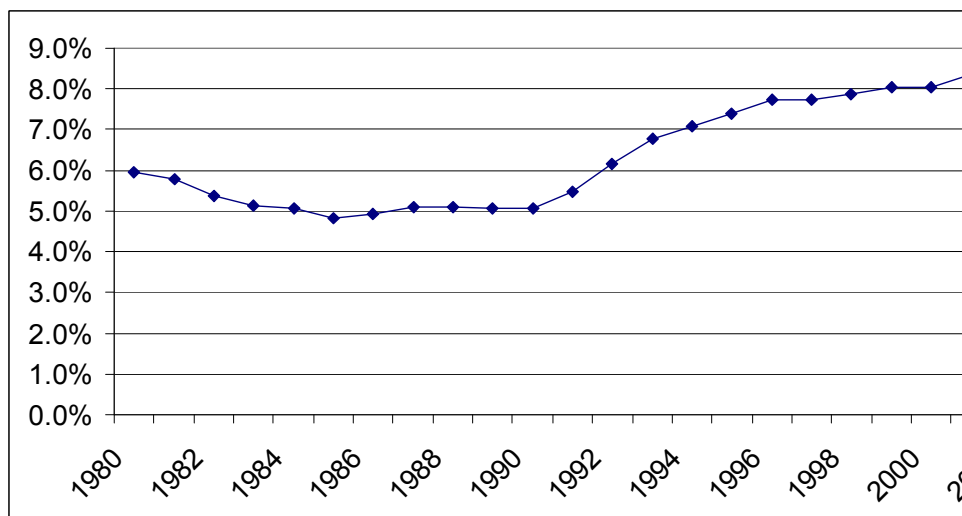
Inflation-adjusted federal spending on SSA's disability programs has grown very rapidly since 1989, both absolutely and as a share of total federal outlays. From 1989 to 2002, total SSDI and SSI-disability expenditures increased by 70.4% after adjusting for inflation, from \$47 billion to \$96 billion (year 2000 dollars, **Exhibit 4**). Although these figures include expenditures for SSI children, which grew rapidly in the early 1990s, it is evident from the exhibit that much of the growth is attributable to SSDI expenditure growth. Further, spending on the disability programs increased substantially as a share of all federal outlays, from 5.1% in 1989 to 8.4% in 2002 (**Exhibit 5**). Spending by the Medicare and Medicaid programs for working-age people with disabilities has likely grown even more rapidly, because of growth in the cost of health care, but historical data on expenditures for the working-age population of those with disabilities are not readily available. In 2000, combined Medicare and Medicaid expenditures for this group were approximately equal to combined SSDI and SSI expenditures.

Exhibit 4. Federal Spending on SSA Disability Benefits



Source: Social Security Advisory Board (2003).

Exhibit 5. Disability Program Spending as a Share of Federal Outlays



Source: Expenditures, Social Security Advisory Board (2003); Federal outlays, President's Council of Economic Advisors (2004).

SSA's actuaries have been warning of impending exhaustion of the OASI and SSDI Trust Funds for many years. In the 2004 Trustees' report, SSA's actuaries projected that the balance of SSDI's Trust Fund will be exhausted in 2029, and the combined OASI and SSDI Trust Funds will be exhausted in 2042. CMS's actuaries projected that the Medicare Hospital Insurance Trust Fund will be exhausted even earlier:

2019. Although the actuaries and trustees have warned the public of pending trust fund exhaustion for at least 15 years, no significant steps have been taken to put the programs back on a sound fiscal footing. As is well known, there have been many proposals, but they are highly controversial. It seems, however, that some reform is inevitable and that disability benefit cuts are likely to be a component of the reforms. Further, most analysts agree that the longer reform is delayed, the more significant benefit cuts are likely to be. Unexpectedly rapid growth in SSDI expenditures is the proximate reason that SSDI Trust Fund is exhausted first, and that growth is contributing substantially to the severity of the overall fiscal problems of these entitlement programs.

History suggests that current growth in disability program spending will eventually lead to tightening of eligibility and/or benefit levels. The most notable example is the administrative tightening of eligibility that began in the late 1970s, under the Carter administration, followed by legislative tightening in the 1980 Amendments to the Social Security Act, implemented in 1981-82. The tightening of this period eventually led to widespread backlash over benefit losses, especially for people with mental illnesses, and a legislated expansion of eligibility in 1984. Expenditure growth in the early 1990s resulted in tightening of eligibility for children, immigrants, and beneficiaries whose drug or alcohol abuse was germane to eligibility. By comparison, the program's current fiscal problems appear far worse.

In short, there is good reason to believe that taxpayer support for the current programs will ultimately be undermined by growing expenditures, threatening the security of many who rely on the programs for support.

Service to Applicants

For years, SSA has found it extremely difficult to provide good service to applicants for disability benefits. Service delivery problems have imposed significant, although inadequately measured, hardships on many applicants, and have likely led to substantial inequities in awards. Although the current administration appears to be making some progress toward improving service, the experience of past Agency efforts to improve service leaves me skeptical that current initiatives will result in an acceptable level of service.

A large share of awards to applicants is made only after an initial denial. In FY2000, almost one third of awards (31.4%) were made after an initial denial. Based on FY2000 data, almost 6 of 10 appeals eventually result in awards.

Many applicants who are initially denied do not appeal, even though high allowance rates for appeals suggest that many would be successful if they did. In FY2000, less than half (47.4%) of initial denials were appealed to the next (reconsideration) level, and only 88% of those denied at the next level were appealed to the Administrative Law Judge (ALJ) level, where most allowances on appeal are made.

Although many awards on appeal might be the result of changes in conditions or information available to SSA, SSA statistics indicate the ALJs disagree with the initial disability examiner's interpretation of the initial evidence. In 2000, SSA's quality assurance reviews of initial denials found that 8.6% were not supported by the evidence in the case file (Social Security Advisory Board, 2001). SSA thoroughly reviewed a sample of over 5,000 ALJ allowances made in 1996 through 1999 and found that 45% were made after reevaluation of evidence from the DDS record, including 11% that were made without a hearing (see Stapleton and Pugh, 2001, Appendix C). Eventual allowances of "initial pre-effectuation review denials" are also suggestive of disagreement over the interpretation of initial evidence between initial examiners, SSA's quality reviewers, and the ALJs. Pre-effectuation review denials are cases that the initial examiner allows, but an SSA reviewer disallows through a review process that is applied to about half of all allowances before the applicant is informed of the award, generally without

collection of new evidence. A study of almost 12,000 such denials made from 1994 through 1997 found that 58.6% were appealed and, of those 47.3%, had been allowed on appeal with another 25.6% still pending a final decision (Stapleton and Pugh, 2001, Appendix E).

Many applicants have to wait months for their initial determination, and many who receive denials, but go on to appeal, wait over a year for a final decision. In FY2003, the average initial processing time for initial disability applications was over three months (97 days), average processing time for appeals to hearing offices was almost a year (344 days), and average processing time for appeals of denials at the hearing stage was another 10 months (SSA, 2003b). These are averages, and they hide the fact that decisions in relatively hard to determine cases take much longer. They also meet SSA's performance goals, which says something about how resigned we have become to the performance of the determination process after years of frustrating efforts to improve it.

Whether or not an initial application is allowed is substantially affected by where the application is filed and which disability examiner happens to review it. It is well known that initial allowance rates vary substantially across states; although it is hard to determine how much of that variation is due to variation in the process rather than variation in the applicants themselves. However, there is good reason to think that process variation plays an important role. A randomized review of test cases that SSA conducted in eight states in 1980 found a range in allowance rates across states of about 10 percentage points. No methodologically sound study of cross-state variation has been conducted since. Changes in the medical eligibility rules introduced in the mid-1980s increased the subjectivity of many decisions, and appear to have contributed to an increase in cross-state allowance rate variation (Stapleton and Pugh, 2001, Appendices C and E). An analysis of 1999 allowance rates for experienced examiners in each of four DDSs, in which each examiner essentially drew application folders at random from a common pile, found that allowance rates varied across examiners by 10 to 20 percentage points more than would be predicted from chance alone (Stapleton and Pugh, 2001, Appendix C).

The determination process likely discourages many applicants from applying, some of whom are likely to be qualified. The length of the process, the requirement that the applicant not work above SGA, and the chance that the application will be denied, imposes a significant cost on applicants. Analyses conducted by Parsons (1991) and Stapleton et al. (1998) demonstrates clearly that exogenous reductions in allowance rates substantially reduce the number of applications in later years.

The determination process likely denies benefits to many people with disabilities who have a significant need for support. Although some denied applicants manage to support themselves through work after being denied benefits, most do not. Like the allowed applicants, many experienced a substantial long-term earnings loss, but they received no assistance. Bound, Burkhauser and Nichols (2003) examined the employment of applicants who applied between 1990 and 1993, and found that only 31% of denied SSDI applicants were employed in the 36th month after their application date, compared to 81% in the 36th month before filing. Thus, it appears that many denied applicants experienced a long-term loss in employment income, but received no support from SSA. Employment rates for denied SSI applicants were even lower in the period after application, but were also quite low in the period before application. Although few denied SSDI applicants might meet SSA's medical eligibility criteria, it seems likely that most have significant medical challenges, yet they receive no assistance.

I have to conclude that SSA's disability determination process imposes a heavy burden on many applicants, results in a substantial number of decisions that are arbitrary and inequitable, is more likely to make awards to applicants who are savvy enough to appeal initial denials in an effective manner than to applicants who are not, and rations scarce benefit dollars by both discouraging

applications from many who meet the medical eligibility criteria, and initially denying benefits to many qualified applicants. Given the substantial misfortunes that have befallen many program applicants, it is hard to imagine how a nation as wealthy as ours can accept it. SSA deserves to be commended for its efforts to address the problems with the process, but I think this is a battle the Agency will never be able to win as long as the program retains its current conceptual definition for benefit eligibility.

The eligibility definition

The 1954 Amendments to the Social Security Act, which established the SSDI program, defined disability as “inability to engage in any substantial gainful activity by reason of any *medically determinable* physical or mental impairment which can be expected to result in death or to be of long-continued and indefinite duration.” (SSA, 1986; emphasis added). The 1965 Amendments replaced “to be of long-continued and indefinite duration” with the less stringent “to last for a continuous period of not less than 12 months.” The 1967 Amendments clarified the definition by stating that a person was eligible “only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.” The same definition was applied to SSI at the program’s 1974 inception, and has not been changed since (Social Security Advisory Board, 2003).

Three features of this definition deserve to be highlighted. First, this definition equates “disability” for programmatic purposes with “inability to work.” The roots of this definition can be found in the “poor laws” of the 17th and 18th centuries, where disability was used as a way to separate those who could work from those who could not—dividing the unemployed into those deserving of aid and those who were able to work and, therefore, not deserving; the “honest beggars” versus the “vagrants.” (Stone, 1984).

Second, this definition of disability embodies the medical paradigm of disability – inability to work is “medically determinable.” The medical paradigm attributes inability to participate in activities such as work to a person’s medical conditions. Researchers, advocates, consumers, and most policymakers have long since replaced the medical paradigm with what I call the medical-environmental paradigm, which recognizes that inability to participate in activity arises because of interactions between a person’s medical condition and the person’s environment. It’s not just the inability to walk that might prevent a person from entering a building, but rather that inability combined with the lack of a wheel chair or the lack of a wheel chair accessible entrance. It’s not just inability to see that might prevent a person from using a computer, but rather the lack of a Braille keyboard or the lack of software that talks. A medical professional can certainly determine whether an individual can walk or can see, but is not equipped to determine whether that same individual can enter a specific building on their own, use a computer, or, more generally, work.

In contrast, the ADA definition embodies the medical-environmental paradigm in its recognition that “accessible buildings and equipment” and “reasonable accommodations” can allow a person to perform a job despite a medical condition that might otherwise prevent the person from doing so. This paradigm is now accepted worldwide, as evidenced by the incorporation of environmental factors in the International Classification System of Functioning, Disability and Health (ICF).

The third feature of the Social Security Act’s disability definition that deserves attention is that it only allows for a yes/no answer. It presumes that there is a black and white line between those who

can work and those who cannot. That presumption is convenient from an administrative perspective. It allows the Agency to treat everybody determined to be on the “eligible” side of the line in the same way (i.e., write them checks for amounts that depend only on their past earnings, other income, and/or assets, but not their medical condition or other circumstances), and allows them to ignore everybody on the “ineligible” side. We know, of course, that life is not that simple. People with disabilities are heterogeneous – as heterogeneous as everybody else, with the added heterogeneity of their medical conditions. Some have a very high earnings capacity, some have absolutely none, and most lie somewhere on a continuum in between.

The consequences of the eligibility definition

The bleak picture painted above can be largely attributed to the conceptual definition of eligibility that is currently used by SSA’s disability programs, and no amount of tinkering with how that definition is implemented will make that picture significantly brighter. Instead, we need to adopt a definition that is consistent with the new disability paradigm. Doing so, however, requires that we adopt an entirely different approach to providing economic security for people with disabilities.

The Income and Economic Independence of People with Disabilities

My colleagues at Cornell and I, along with a number of other researchers, have extensively studied the likely causes of the employment rate decline of the 1990s. Some have reached the highly controversial conclusion that the cause of the decline is the ADA itself (DeLeire, 2000, 2003; Acemoglu and Angrist, 2001). The evidence they cite comes from the fact that the beginning of the employment decline coincides with the 1990 passage of the ADA and its 1991 implementation. They argue that the ADA imposes new costs on employers when they hire people with disabilities: the costs of “reasonable accommodations” and the costs of potential litigation over promotion or termination decisions. These costs, in combination with the difficulties of enforcing provisions against discrimination in the hiring process, presumably have deterred employers from hiring people with disabilities.

Many find this conclusion hard to accept. They point out that the Civil Rights Act of 1964 has been shown by economists to have increased the employment of African Americans, and that we should expect the ADA to do the same for people with disabilities. They argue that the ADA and activities surrounding its implementation have reduced discrimination, made employers more aware of the capabilities of people with disabilities, made them more knowledgeable about how to accommodate workers with disabilities, made them more careful to incorporate universal design features in the their buildings and equipment, and made it easier for their workers with disabilities to get to work.

Although it is hard to refute the coincidence of the beginning of the employment rate decline and the passage of the ADA, there are many competing explanations of the decline. Burkhauser and Stapleton (2003b) review the evidence concerning the competitors carefully, and conclude that the most compelling alternative explanation of the decline is a pair of gradual changes in SSA’s disability programs. The first is liberalization of eligibility, particularly for those with conditions that are difficult to accurately diagnose: mental illnesses (especially severe affective disorders) and musculoskeletal conditions (especially conditions that cause lower back pain). This liberalization started with the 1984 Amendments to the Social Security Act, which were largely a reaction to the tightening of eligibility a few years earlier. Liberalization continued through the regulatory process and a long series of court cases, well into the 1990s. The second is a gradual increase in the SSDI replacement rate for low-skill workers, which occurred because the contribution of an applicant’s past earnings to the SSDI benefit amount is indexed to average wage growth, and wages of low-skill workers grew more slowly than those of others. The first change made more workers eligible for the

program, and the second change increased the attractiveness of benefits relative to work for low-skill workers.

The last important piece of the story is that the recession of 1990 triggered a flood of newly eligible individuals into the program. The strong economy of the late 1990s presumably made it unattractive for many such workers to apply for benefits when eligibility was first liberalized. These so-called “contingent applicants” had jobs, and application would have meant giving up those jobs with no guarantee that benefits would be awarded. When contingent applicants lost their jobs during the recession, application for benefits suddenly became costless and they applied.

The empirical evidence, reviewed by Goodman and Waidmann (2003), is compelling. As Bound and Waidmann (2002) have shown, entry into SSDI closely tracks the exits from work of people with disabilities throughout this period. The fastest growing impairment categories for beneficiaries have by far been those affected by the liberalization in eligibility criteria. Evidence presented by Autor and Duggan (2003) shows that the declines in employment and increases in program participation were greatest for those with the least skills and lowest potential wages. They also show that employment and program participation for people with disabilities have become much more sensitive to recessions than they used to be.

Just in the past few months, Burkhauser and Houtenville (2004) have used the CPS to produce estimates of employment trends for people who report a work limitation in each of two interviews, approximately 12 months apart. This addresses one of the limitations of the CPS work limitation question – failure to adequately distinguish between short- and long-duration limitations. There is a substantial employment rate decline for this group, and it begins shortly after passage of the 1984 Amendments. Thus, it appears that the subpopulation with longer term disabilities, who are more likely than others to be eligible for SSDI, were reducing their employment well before the ADA was passed.

Adding to the weight of all this evidence is a substantial literature that had previously established a strong link between the availability and value of SSA disability benefits, on the one hand, and both employment and program participation on the other.

The most important lesson from this is not that we’ve made the definition of eligibility too liberal or that benefits are too high for low-skill workers. Instead, the lesson is that, in a world where medical advances, accommodations and accessibility make it increasingly difficult to medically determine who can and cannot work, attempting to draw a medically determined line between those who can work and those who cannot, and giving benefits only to those on one side of the line, is inevitably going to leave many people with significant medically-determinable conditions with a difficult choice: to seek benefits and give up their economic independence, or to continue to support themselves and their families through work. Many will face significant economic hardship under either option. They will not have the option that they may really need: one that helps them lift themselves out of poverty.

Put differently, the disability programs create a major work disincentive for many people with disabilities. If people with disabilities work at a level that is below SGA, they can receive benefits; if they increase their earnings they lose their benefits. The root cause of the disincentive is the definition of disability. The notion that there is a medically determinable line between those who can and cannot work is a legislated fiction. As a result, SSA must rely on an earnings test as well as a person’s medical condition. That’s the reason the programs discourage work – people who meet the medical criteria but nevertheless work can only obtain benefits if they work less or stop work entirely. Because the law requires SSA to live by the fiction that inability to work is medically

determinable, the disability programs will discourage large numbers of people with disabilities from trying to support themselves.

Expenditure Growth and Taxpayer Support

As long as SSA's disability programs continue to use the same conceptual definition of disability for eligibility purposes, they will periodically experience rapid expenditure growth that undermines taxpayer support for the programs, and that ultimately triggers cutbacks, thereby undermining the economic security that the programs are intended to provide. The reason that expenditure growth is inevitable is that the programs do not help many people with significant medical conditions who either do not meet program eligibility criteria, or who meet them but are denied benefits. That generates pressure from people with disabilities and their advocates to liberalize the eligibility definitions. When budgets are not exceptionally constrained, that pressure results in liberalization of the definition through administrative, judicial and legislative means.

Some of those affected by such liberalizations will find that obtaining benefits has become a better option than work, although perhaps only with a delay -- after an adverse economic event leaves them unemployed. Eventually, expenditures increase beyond levels that taxpayers will support, as they did in the 1980s and again in the early 1990s. Taxpayers can see that many people who receive benefits could work, and they know who is paying to support those same people. I predict that we will see cuts in the next 10 years, greater in magnitude than any we have seen before, unless we stop clinging to the programs' current disability definition and make fundamental changes in how we provide economic security for people with disabilities.

Service to Applicants

SSA will never be able to make substantial improvements in the services it provides to applicants unless the statutory definition of disability is changed. SSA's job is to medically define the bright line between those who can and cannot work, and determine which side of that line each applicant is on. This is an impossible task, because no such line exists.

One response to that dilemma has been to move away from a purely medical definition, to consider so-called vocational factors. This does not, however, solve the problem. There is no clear line between those who can and cannot work; instead, how much an individual can reasonably be expected to earn depends on a constellation of medical issues, other personal characteristics, and environmental factors. Further, these factors are constantly changing, as the economy changes, new medical treatments are developed, and accommodations for people with disabilities improve (Stapleton, 1999).

SSA's adjudicators are engaged in determining which side of a fictitious line each applicant is on. That is ultimately the reason why it takes them so long to gather information and make decisions in many cases. It is the reason why two examiners working in the same state office can have award rates that vary by 10 to 20 percentage points more than we would expect from chance alone. It is the reason why 8 percent of initial denials reviewed by SSA are not supported by the evidence presented by the examiner. It is the reason why about half of pre-effectuation review denials are eventually allowed on appeal. It is the reason why administrative law judges allow almost half of the cases they receive on the basis of information that was available to the initial disability examiner. It is the reason why the majority of applicants who are denied benefits do not return to work; they needed help, but were determined to be on the wrong side of a fictitious line. It is the reason why SSA has made so little progress in improving the disability determination process after a concerted, expensive effort that has lasted over a decade.

To change the eligibility definition, we also have to change our approach to providing economic security for people with disabilities.

The current disability programs use a “caretaker” approach to providing economic security for people with disabilities. That is, they try to identify those who are unable to work, then take care of them by providing income support and medical benefits. The caretaker approach requires that we determine who can work and who cannot. If we want to continue with this approach as the dominant approach, then we have to stay with an eligibility definition that attempts to distinguish those who can work from those who cannot. We could attempt to bring the program in line with the new disability paradigm by moving away from a purely medical definition toward one that explicitly considers the role of the environment, but the environment is so complex and so dynamic, and how it affects individuals with disabilities is so heterogeneous, that we could never do so in a satisfactory way (Stapleton, 1999).

The only way we can have eligibility rules that are consistent with the new disability paradigm is to change our primary approach to providing economic security, to an approach that is also consistent with the new paradigm – an approach of helping people with disabilities help themselves. Such a “self-support” approach would be consistent with the aspirations of the disability rights movement. It would also be consistent with basic human values, and would likely garner widespread support from taxpayers. And it would allow people with disabilities to have more fulfilling lives and contribute more to society.

A self-support approach would need eligibility rules, to be sure. The first-line eligibility rules could be medical rules that are designed only to identify people who face significant medical challenges in their lives – challenges that could result in inability to work if appropriate supports are not available. Actual engagement in work would be irrelevant to the determination process. Such a process would be easier to administer than the current process because it would not require adjudicators to assess ability to work, and applicants would not have an incentive to demonstrate that they cannot work; instead, they would be seeking supports that would help them take care of themselves.

Under such a system, most who qualify would be expected to work at some level, and would be provided with employment support services. Those able only to attain low-wage jobs or work limited hours could be offered wage subsidies or tax credits that would both provide them with an incentive to work and improve their standard of living. Those with the most severe conditions would be provided with income support that would not be conditioned on earnings unless earnings were very high. Those in the oldest age group (e.g., 50+) might be given access to their retirement benefits on an actuarially fair basis, not conditioned on earnings, and perhaps adjusted for the effect of their medical conditions on their life expectancy. Health insurance benefits designed for people with disabilities would be independent of work status and available for life, but under certain conditions the beneficiary and/or the beneficiary’s employer would be expected to pay a share of the cost.

There are, however, many significant challenges to establishing such a program. Can we afford such a program? Can we muster the resources from the multiplicity of largely independent public programs that now serve people with disabilities, all with their own self-interested stakeholders? How can a government bureaucracy effectively administer benefits that are tailored to the support needs of an extremely heterogeneous population? Most importantly, how can we avoid irreparably harming millions of those we intend to help as we transition to a new system, and experiment with the new approach?

Although I have some ideas about how to answer these questions, I certainly do not have all the answers. I think there are some things we can learn from the experiences of other countries that have moved further in the direction of “self-support” first policies, such as Germany and Sweden. I also think we can learn from our own experience with providing economic security for families with children (Stapleton and Burkhauser, 2003; Burkhauser and Stapleton, forthcoming). For decades we took a caretaker approach, and our patchwork efforts to address persistent declines in self-support and growth in dependency were unsuccessful. We changed to a self-support approach in the 1990s. Specifically, in 1993 we greatly increased the Earned Income Tax for families with children, to greatly increase the value of work for parents with limited skills. Then, in 1996 we changed our approach from a long-term caretaker approach to a short-term, “work-first” approach. Researchers agree that the combination of these changes, aided by a strong economy, caused the unprecedented growth experienced by single mothers in the latter half of the 1990s, and the unprecedented decline in welfare caseloads. All this occurred at the same time that the employment of people with disabilities was declining, and their dependence on disability benefits was increasing. The differences in what happened to these two populations in the last decade is stunning.

I do not mean to suggest that the experience of welfare reform was an unmitigated success, or that it can be applied straightforwardly to disability policy. In fact, one of the failures of welfare reform is that it segregated parents with disabilities by not providing the support they need to support themselves. Instead, most states gave them exemptions from work requirements and time limits, or pushed them on to SSI. Welfare reform does, however, provide reason to think that changing our approach to disability policy can reverse the discouraging trends we have seen since the late 1980s. We would do well to think more carefully about how lessons from that experience can potentially be applied to disability policy.

Most importantly, we need to be asking ourselves, and debating the answers to, the types of questions I have raised, rather than spending all of our time and energy trying to patch up the disability programs. We have been trying to move away from the caretaker approach to providing support for people with disabilities, through work incentives, improved financing of rehabilitation services, investments in technical innovations, improved education, separation of medical benefits from income benefits, and civil rights legislation. We have been trying to keep expenditure growth under control, through changes in eligibility rules and administrative steps to protect the financial integrity of the programs. We have been trying to provide better services to applicants, by tinkering with the determination process. The record shows that these efforts have, on the whole, failed. The reason is simple: the disability programs continue to use an eligibility definition that buys in to the widely discredited medical model of disability. Inability to work is not medically determinable.

The new disability paradigm tells us that determination of inability to work is an impossible task, because the environment matters. If public disability programs are to embrace the new paradigm, they can no longer require determination of inability to work for their administration. They have to change their primary approach to providing economic security from the current caretaker approach to an approach that emphasizes helping people to help themselves.

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